

## INVITED COMMENTARY

# The first 100 years of the ILAE (1909-2009): Its landmarks, achievements, and challenges

Simon D. Shorvon 

UCL Queen Square Institute of Neurology, University College London, London, UK

## Correspondence

Simon D. Shorvon, Institute of Neurology, UCL, Box 5, NHNN, Queen Square, London, WC1N 3BG, UK.

Email: s.shorvon@ucl.ac.uk

**KEYWORDS:** epilepsy, history, International League Against Epilepsy

## 1 | INTRODUCTION

The article was commissioned for the 110 anniversary of the founding of the ILAE, to provide a short summary of ILAE history, listing not only its landmarks and achievements but also its challenges. The League is an extraordinary, complex, and multifaceted organization, and within the small space allowed only the briefest and selective account is possible (and taken largely from its centenary history book<sup>1</sup>) (Figure 1). It is with these caveats, and with the reader's forbearance, that this article should be read.

## 2 | THE FOUNDATION OF THE ILAE, AND ITS FIRST FIFTY YEARS (1909-1958)

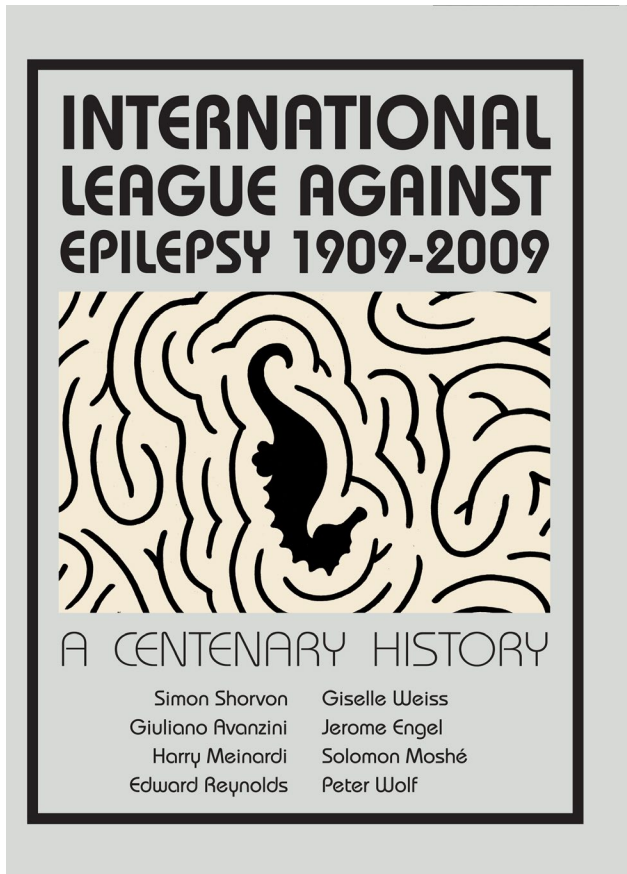
The League came into being at the 16th International Medical Congress in Budapest held on 29 August–4 September 1909. The congress was one of those gorgeous and glittering affairs, typical of the Edwardian age and which rather put modern conferences to shame. It was there, in a small private room, the Salle Donau, of the Hotel Bristol, that 46 persons met to found the League. The date was August 30, 1909. Eminent figures were present and the League boasted the patronage of celebrated physicians including Alt, Hebold, Friedländer, Bechterew, Raymond, Landouzy, Sommer, Weigandt, and Tamburini. The journal *Epilepsia*, formed a few months earlier, was adopted at the meeting as the “official organ” of the League, with an equally renowned “committee of patronage”

of Bechterew, Binswanger, Jackson, Luciani, Raymond, and Obersteiner. At the opening meeting, a statement of purpose (its “mission”) was declared: “The League will devote itself to special projects on behalf of epileptics, and to finding a cure and means of prevention, as well as providing aid and social rehabilitation.” It was an auspicious start, and the process of foundation was rather typical of a range of similar international collaborations in other disciplines in Europe at the time. Membership was conferred on individuals who paid annual membership fees and who were grouped into national branches. By the time the first membership list was printed (in *Epilepsia*) in 1911, there were 96 members from 19 different countries. Most of the founding members were alienists (psychiatrists practicing in asylums) and indeed at the time, asylums (epilepsy colonies) were considered the most appropriate setting for people with epilepsy. Its first special project was a grandiose plan to collect information about scale of the problem of epilepsy:

All countries were to prepare statistics on a wide range of topics: the numbers of new non-institutionalised and chronic institutionalised cases; the number of existing hospitals and colonies, and their admission rates (for new and chronic cases); and the number of patients treated both as inpatients and outpatients in the various private and public hospitals and sanatoriums over the past 5 years. Governments should be requested to collect official statistics on epileptics in their country. The military, too, should be asked to give the number of epileptic recruits. Individual countries might provide an overview of aid

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2019 The Authors. *Epilepsia Open* published by Wiley Periodicals Inc. on behalf of International League Against Epilepsy.



**FIGURE 1** Cover of *International League Against Epilepsy 1909-2009: a centenary history*. The Figure has been reproduced with permission from reference<sup>1</sup>

for epileptics, as well as the number of sufferers determined by the most recent census. In carrying out their investigations, governments would be advised of the high degree of criminality among epileptics.

A year later, its next meeting was held in Berlin, during the 4th International Congress for the Care and Treatment of the Insane, with 11 members present. Tamburini was appointed president and Donath as secretary, statistical reports were presented from Great Britain, Holland, and Sweden, and two scientific papers were presented (on “Criminality among epileptics” (by Veith) and “Physiopathological research in epilepsy” (by Muskens)). The next meetings were in Zurich in 1912 and London in 1913 as part of the (formidable) 17th International Medical Congress. By then, a constitution had been agreed, with a structure very similar to today’s. The League had made a good start, but in 1914, before the planned next meeting in Berne could take place, Europe was plunged into war and all activities were brought to a premature end.

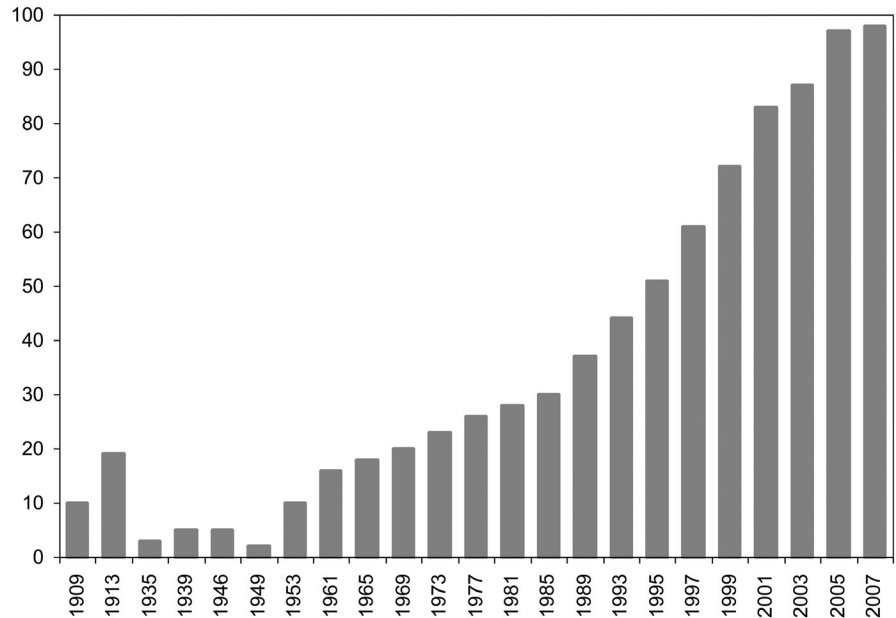
Between 1914 and 1935, the League ceased to exist. After 1918, other international medical and neurological organizations had been re-established, and although there was talk of reviving an epilepsy organization, this failed to materialize.

Then, in 1935, at the 2nd International Congress of Neurology in London, the ILAE was successfully relaunched. The first meeting of the revived League, with 32 doctors from 14 countries present, was held at the Lingfield epilepsy colony close to London. Officers were appointed, of whom Louis Muskens from Amsterdam was the only figure who had been an officer in its earlier phase. Muskens urged the “presidency of the newly formed ILAE should be an American uninvolved with the politics of Europe, which had proved so disastrous” and William Lennox was appointed president. He wrote that he was in Lingfield as “an innocent bystander” in place of [Stanley] Cobb, who had been at short notice unable to attend, but his presidency was to prove of great importance to the future League. 3 chapters (branches) were reformed—the British, American, and Scandinavian—and by 1936 there were 219 members from these countries.

In 1937, publication of *Epilepsia* was also restarted. As Lennox wrote: “All are agreed that the first and foremost enterprise [of the League] is the publication of ‘Epilepsia.’” In 1939, he published a paper in the journal entitled “The future of the International League Against Epilepsy,” urging that branches be set up in as many countries as possible: “for the ability of an organism to reach its destination depends on its legs and on its powers of co-ordination. In our organization, the branches in various countries are the limbs, and the officers and ‘Epilepsia’ provide for co-ordination.” Size was to be no bar—and he cited the example of Czechoslovakia. He lamented the lack of interest in France, Germany, and Italy and then ended his piece with an unusual sentiment: “The world is desperately in need of people who will work together for the good of mankind. Therefore, in addition to scientific and humanitarian aspects our League plays a part in maintaining the stability of civilisation.” This proved overoptimistic, as within 6 months the world was again engulfed in war. The next meeting of the ILAE, in 1939, was in Copenhagen, and as Lennox later wrote “the banquet had been a tragic affair as the congress was interrupted by the start of the German blitzkrieg” (actually this did not start until 6 days later, but the atmosphere was no doubt gloomy and foreboding).

During the War, all activity of the ILAE ceased, apart from the publication of *Epilepsia* which had moved to Lennox’ office in Boston. He kept the journal going despite many difficulties and the organization did not disappear as it had done during WW1. As soon as hostilities ceased, plans were made for its revival, and in 1946, the next meeting was held in New York, as part of the meeting of the Association for Research in Nervous and Mental Diseases. The delegates were American with the exception of a handful of British and Dutch representatives who had made it to America, and

**FIGURE 2** The growth in the number of ILAE national chapters between 1909 and 2009. The Figure has been reproduced with permission from reference<sup>1</sup>



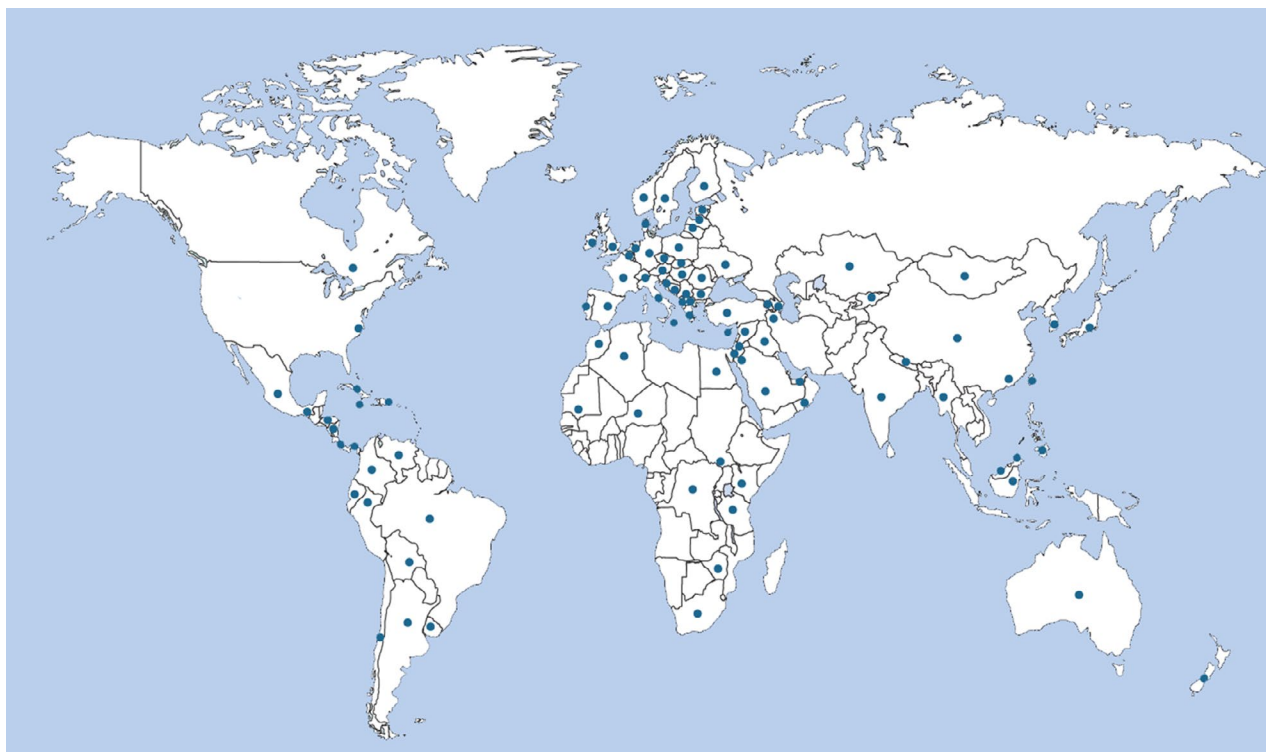
there was an ambitious programme of 45 papers, including contributions by Temkin, Margaret Lennox, William Lennox, the two Gibbsses, Ward, Penfield, Jasper, Merritt, Bailey, Fay, Schwab, Livingston, and Grey Walker. EEG featured prominently, as did novel antiepileptic drugs, as well as five papers on epilepsy and war. The discipline of epilepsy had been given a new stimulus by the introduction of EEG and innovative treatments, and the meeting marked a new beginning for the League. The next meeting was in Paris in 1949, in conjunction with the Congress of the International Society of Electroencephalography and the International Congress of Neurology. An ILAE business meeting and three sessions on epilepsy took place. Following this, meetings (quadrennial meetings) occurred every 4 years: in 1953 in Lisbon devoted to the new topic of Temporal Lobe Epilepsy, and in 1957, in Brussels where it was assigned a place on the first morning of the International Congress of Neurology and with speakers including Critchley, Buchthal, Grey Walker, Gibbs, Penfield, and Gastaut.

So, in summary, what had been achieved in these first fifty years? The League's fortunes had waxed and waned. Its main activity was the holding of annual meetings. These were, at the start, single day meetings, with an agenda of primarily administrative matters, a few scientific presentations and sometimes a visit to the local asylum, attended by as few as 10 people. The League took the form of a "club," with grandiose plans initially, but these were terminated by the First World War and when the League was briefly revived in 1935, it was again rendered inactive by the second. It had been dominated by Europe prior to the Second World War and then after the War by the United States. From 1946, under the stimulus of Lennox, the conferences assumed a much larger scale and were devoted largely to scientific topics. Its journal

*Epilepsia* too had had its ups and downs. In the 1950s, though the League was going through another difficult period. It was still a small organization, with only seven national chapters (Argentina, France, Britain, Japan, Netherlands, Peru, and the United States) and in 1955 *Epilepsia* had ceased publication. In the United States, after Lennox had stepped down, most activity in epilepsy became centered on the American Epilepsy Society rather than the international body. Epilepsy as a topic had been greatly stimulated by the introduction of EEG and the hydantoin drugs, but these were independent of the League. Tensions about the relative importance of the social and scientific agendas, both in relation to the role of *Epilepsia* and of the League generally, had bubbled to the surface and were the source of much disagreement among the executive. The League also had a shaky financial base of only around \$3000, and one senses a flagging interest in the organization's relevance or importance as it had moved away from its initial goals.

### 3 | THE SECOND FIFTY YEARS OF THE ILAE (1959-2009)

The 1960s proved to be a turning point. The seeds had been sown by Lennox, but the League began fully to flower under the leadership of Henri Gastaut. The major stimulus was the development of a new classification of epileptic seizures, which was largely Gastaut's personal creation although he badged it "The ILAE classification" made "under the auspices" of the ILAE. He managed to push it through despite a variety of alternative schemes (including those proposed by the ILAE Presidents McNaughton and Merlis, and Richard Masland) and after several revisions, the classification was



**FIGURE 3** A world map of ILAE chapters in 2009. The Figure has been reproduced with permission from reference<sup>1</sup>

approved by the ILAE general assembly and was published in 1970 in *Epilepsia*. It has become universally adopted, no doubt in large part due to Gastaut's untiring promotion, his bullying and his manipulation of WHO, WFN, EEG society, and other international organizations. The ILAE had before this not undertaken any real activity other than the holding of congresses and the publication of *Epilepsia*, and the tagging of the classification with the ILAE name was a coup for the organization. By virtue of this, the ILAE became synonymous with professional authority in epilepsy and in the Snakes and Ladders game of international neurology, this single activity catapulted the ILAE into the top position in the epilepsy world. The League then entered a period of growth, uninterrupted by any global war (although at times, this seemed close) and stimulated toward the end of this period by the changing contexts of globalization and the triumph of international capitalism. In the short space available, here is a synoptical view of some ILAE landmarks and activities in this period:

### 3.1 | Membership

When founded, individuals were considered members and the League collected its membership dues from each individual. However, when the League was restarted in 1935, the "members" were the national branches, and dues were collected from the branches (subsequently named chapters) at a sum which depended on the number of members of each branch. After 1959, the number of branches began to increase progressively.

15 chapters existed in 1961, 30 chapters in 1973, 48 in 1995 and by 2007 there were 98 chapters (see Figures 2 and 3). Some chapters comprised very few members but others were large, and it was estimated that there were over 15,000 individual members of national chapters by 2009.

### 3.2 | Congresses

A core function of the ILAE, since its inception, has been the holding of congresses. Since 1949, a continuous series of international congresses has taken place every 4 years between 1959 and 1977, then annually (as Epilepsy International Symposia) between 1978 and 1983, and then every two years from 1985. Initially, the ILAE sessions were part of a larger international meeting of another medical organization. They were then held as separate entities at the same venue immediately before or after an international neurological and/or neurophysiological congress. After 1978, some meetings were attached to the World Congress of Neurology meetings, but then since 1985, the congresses became sufficiently financially and scientifically robust to be held as entirely stand-alone events. The congresses were one-day meetings until 1973, with modest programmes and without commercial sponsorship. The first satellite meeting was held in 1982, and since then the congresses rapidly expanded. By 2009, they were 5-day meetings with five or six plenary themes, parallel sessions, breakfast sessions, and workshops, satellites, and in some with over 5000 delegates registering (Table 1).

**TABLE 1** The 56 International and regional meetings of the ILAE held in 36 countries—a testament to the internationalism of the ILAE

Year	Title of the meeting	Location	Country
1909	ILAE Meeting	Budapest	Hungary
1910	ILAE Meeting	Berlin	Germany
1912	ILAE Meeting	Zurich	Switzerland
1913	ILAE Meeting	London	Great Britain
1935	ILAE Meeting	Lingfield	Great Britain
1939	ILAE Meeting	Copenhagen	Denmark
1946	ILAE Meeting	New York	USA
1949	ILAE Meeting	Paris	France
1953	ILAE Meeting	Lisbon	Portugal
1957	ILAE Meeting	Brussels	Belgium
1961	ILAE Meeting	Rome	Italy
1965	ILAE/IBE Meeting	Vienna	Austria
1969	11th ILAE/IBE Congress	New York	USA
1973	12th ILAE/IBE Congress	Barcelona	Spain
1977	13th ILAE Congress/9th IBE Symposium	Amsterdam	Netherlands
1978	10th Epilepsy International Symposium	Vancouver	Canada
1979	11th Epilepsy International Symposium	Florence	Italy
1980	12th Epilepsy International Symposium	Copenhagen	Denmark
1981	13th Epilepsy International Symposium	Kyoto	Japan
1982	14th Epilepsy International Symposium	London	Great Britain
1983	15th Epilepsy International Symposium	Washington	USA
1985	16th Epilepsy International Symposium	Hamburg	Germany
1987	17th Epilepsy International Epilepsy Congress	Jerusalem	Israel
1989	18th Epilepsy International Epilepsy Congress	New Delhi	India
1991	19th Epilepsy International Epilepsy Congress	Rio de Janeiro	Brazil
1993	20th Epilepsy International Epilepsy Congress	Oslo	Norway
1994	1st European Congress on Epileptology	Oporto	Portugal
1995	21st Epilepsy International Epilepsy Congress	Sydney	Australia
1996	2nd European Congress on Epileptology	The Hague	Netherlands
	1st Asian and Oceanian Epilepsy Congress	Seoul	South Korea
1997	22nd Epilepsy International Epilepsy Congress	Dublin	Ireland
1998	3rd European Congress on Epileptology	Warsaw	Poland
	2nd Asian and Oceanian Epilepsy Congress	Taipei	Taiwan
1999	23rd Epilepsy International Epilepsy Congress	Prague	Czechoslovakia
2000	4th European Congress on Epileptology	Florence	Italy
	3rd Asian and Oceanian Epilepsy Congress	New Delhi	India
	1st Latin American Epilepsy Congress	Santiago	Chile
2001	24th International Epilepsy Congress	Buenos Aires	Argentina
2002	5th European Congress on Epileptology	Madrid	Spain
	4th Asian and Oceanian Epilepsy Congress	Nagano	Japan
	2nd Latin American Epilepsy Congress	Fos do Iguassu	Brazil
2003	25th International Epilepsy Congress	Lisbon	Portugal

(Continues)

TABLE 1 (Continued)

Year	Title of the meeting	Location	Country
2004	6th European Congress on Epileptology	Vienna	Austria
	5th Asian and Oceanian Epilepsy Congress	Bangkok	Thailand
	3rd Latin American Epilepsy Congress	Mexico City	Mexico
2005	26th International Epilepsy Congress	Paris	France
2006	7th European Congress on Epileptology	Helsinki	Finland
	6th Asian and Oceanian Epilepsy Congress	Kuala Lumpur	Malaysia
	4th Latin American Epilepsy Congress	Guatemala	Guatemala
	1st North American Epilepsy Congress	San Diego	USA
2007	27th International Epilepsy Congress	Singapore	Singapore
2008	8th European Congress on Epileptology	Berlin	Germany
	7th Asian and Oceanian Epilepsy Congress	Xiamen	China
	5th Latin American Epilepsy Congress	Montevideo	Uruguay
	2nd North American Epilepsy Congress	Seattle	USA
2009	28th International Epilepsy Congress	Budapest	Hungary

Note: NB: Included here are 1909 meeting in Budapest and the 1935 meeting in Lingfield which were foundation meetings, not scientific meetings).

In the last two decades, the ILAE formed regions (see below) and each region also held its own congresses alternating with the biennial ILAE international epilepsy congresses (IEC). Again, this move was led by the European region, and the European Epilepsy Congresses especially grew rapidly in size and scope with delegate numbers sometime exceeding those of the IECs. For many years too, national congresses were held each year in most countries (or sometimes groups of countries). Their great number was possible because of pharmaceutical industry support, and this raised issues discussed below. Furthermore as scientific progress was sometimes insufficient to support so many meetings, there was not infrequent redundancy and repetition. Nevertheless, these congresses have provided outstanding opportunities for international networking and collaboration and have cemented the League together as a coherent international body.

### 3.3 | Epilepsia

*Epilepsia* has a complex publishing history. It was produced in four series: series I, 1909–1914/15; series II, 1937–1950; series III, 1952–1956; and series IV, 1959/60 to the present day. The first series was primarily a scientific enterprise, and therein were interesting and important papers. There were also reports of ILAE activities and critical abstracts of epilepsy publications elsewhere. This first series made a promising start and its premature discontinuation, on the advent of WWI was a great loss.

When the second series was launched, the ILAE decided that the publication of scientific papers should not be the main focus, but that instead *Epilepsia* should abstract the scientific literature from elsewhere and act as a record of

ILAE activity. The first editor of the second series, wrote that “The first aim of the reorganised League must be the social care of epileptics and not so much scientific research into epilepsy. The new edition of *Epilepsia* must follow these lines. It must be the organ for our league.” Its initial issues contained chapter reports, programmes of annual meetings and also summaries of statistics of epilepsy from different countries, as well as abstracts and bibliographies. During the Second World War, publication was moved to America and during this time mainly provided a bibliography of abstracts, occasional papers, and reports of the American chapter. This was not a successful formula but the journal limped on.

In 1949, the decision was made to terminate temporarily the publication of the 2nd series of *Epilepsia* and to set up a committee to study the value and viability of the journal. It was widely recognized that as an annual abstract journal, “*Epilepsia* had lost much of significance.” The ILAE executive was split on the question of what role *Epilepsia* should have, but eventually decided that a third series should be published under the auspices of the publishing committee of the American Branch of the ILAE and not publish original articles, as there were many journals already doing this, but concentrate on critical reviews. The executive also wanted *Epilepsia* to “be more evidently the journal of the International League” and contain reports from its branches. The resulting annual publication was rather a curate’s egg, with a mixture of science and non-science, and was not successful, and in 1955, the ILAE again abandoned publication to consider its position.

A fourth series was decided upon and launched with Sir Francis Walshe, who was previously editor of *Brain*, chosen

as the new editor. He had a clear vision of the journal as an organ for “informed, original and critical studies” covering all fields of epilepsy research. So was the current model of the journal launched and the series continues to this day as the leading scientific journal in its field, publishing original basic and clinical research. Limited space was given to ILAE activities when the journal launched its “Gray Matters” section in 2007.

### 3.4 | The International Bureau against Epilepsy (IBE) and Epilepsy International (1971-1984)

At the ILAE congress in Rome in 1961, the Mosovich motion proposing the setting up of a separate grouping of national lay persons epilepsy associations was passed, and the IBE came into existence. How it should interact with the ILAE was immediately, and has remained, a controversial issue. In 1966, Lorentz de Haas, the ILAE president, wrote to the ILAE executive: “The Bureau has since carried out a variety of tasks and developed laudable activities.... It is perhaps understandable that the Bureau has done so in a position of considerable independence. The question, however, is whether this independence has not assumed proportions reaching farther than has ever been the intention of the Committee of the International League.” Already, friction had arisen between the ILAE Secretary-General (Gastaut) and the head of the Bureau (George Burden), and a turf battle was developing. De Haas continued: “While we may gratefully acknowledge all that the International Bureau in London has so far done, we must bear in mind (as must the Bureau) that it is closely linked to the League and owes its appellation ‘International’ to the League. Should the Bureau fail to understand this, then the League could in fact establish another bureau at any time, anywhere in the world.” Gastaut was more blunt: “You know that for a long time I have considered that the Bureau’s insufferable independence diminishes the effectiveness of the League, and that this competition between two organisations that have the same goals is ridiculous and intolerable.” Various schemes to bring the two organizations together were discussed and then in 1971 integration into a single body—the “International Epilepsy Foundation” was proposed. Over the next 8 years, after much argument and some bitterness, it was agreed that both organizations should share joint programmes, meetings, a newsletter and fundraising activity and open a shared office and administrative staff—under the umbrella of “Epilepsy International” and that if this went well “it was the aspiration of some on the executives that the League and the Bureau would merge into a single entity, subject of course to the approval of the chapters.” The next years were complicated by arguments over cost of travel, membership, constitution, and *Epilepsia* ownership but eventually in 1977, joint “Epilepsy International” congresses were held annually

and additional workshops. After a period when two offices were run from London and Washington, it was agreed to have a single office in Geneva. Continuing problems over money arose but in 1980, the IBE executive agreed to a full merger, but the ILAE voted against. Epilepsy International funds were cut and in 1984 it too was wound up. Finance was a core issue and the proposal had been predicated on the opportunity it provided for fundraising, but Epilepsy International never managed to raise the required sums. The advocacy of a few key individuals gave the initiative momentum, but the support from the majority was never more than lukewarm. It was a bruising episode in ILAE history, consuming much time and effort, and causing much ill-feeling. The proceedings of Epilepsy International annual meetings were published in book form, and are now the only concrete remains of this episode in the ILAE’s history.

### 3.5 | ILAE commissions

After the success of the Commission on Classification and Terminology, in 1974 a Commission on Antiepileptic Drugs was appointed. This too was a highly successful exercise, influencing policy in this area. In 1986, a second Commission on Classification and Terminology produced the ILAE Classification of the Epilepsies and Epileptic Syndromes which was also published in *Epilepsia* and successfully adopted by the international community. Since then, the number of commissions grew to 14 in 1993 (not including the regional commissions, of which more later) but none have been as successful as the earlier examples, and indeed some produced no output of value. Criticism mounted about money being wasted and the commissions were then reined in, although by 2009 there were still nine in existence. It is through these Commissions that ILAE policy was developed and special projects enacted, but the criticism was that some had degenerated into talking shops with little strategic thinking and diffuse governance.

### 3.6 | Regional commissions

As the number of chapters grew, there was increasing pressure for a tier of administration to be put in place between the national chapters and the international executive, to give individuals and national chapters more influence. In 1992, tensions reached boiling point, and arrangements for a pan-European scientific meeting outside the purview or control of the ILAE were made. This meeting, *Epilepsy Europe*, was held by a new non-ILAE group calling itself the *European Society for Epilepsy* and began to solicit support from pharmaceutical companies. The ILAE responded by setting up a “Commission on European Affairs” and a “European Advisory Council” (EAC). The commission comprised eight members, and its remit was to improve lines of communication within Europe and to further the

objectives of the League regionally. The EAC was designed to be a “parliament” for the European chapters, with every chapter having a single seat and a single vote. This structure was established with the intention of giving each chapter a stake in the work and activities of the region and to act as a buffer against any more extreme ideas. This worked. The nascent *European Society for Epilepsy* disappeared, and the ILAE retained its control over international epilepsy matters. Simply put, the ILAE was by then too large to exist without a regional tier, and within a few years, there were regional commissions and advisory bodies formed in five regions. The European region remained the largest with 42 member countries in 2009, compared with 17 in the South American region, 17 in the Asian and Oceanian region, 10 in the African region, nine in the Eastern Mediterranean region, and only three in the North American region.

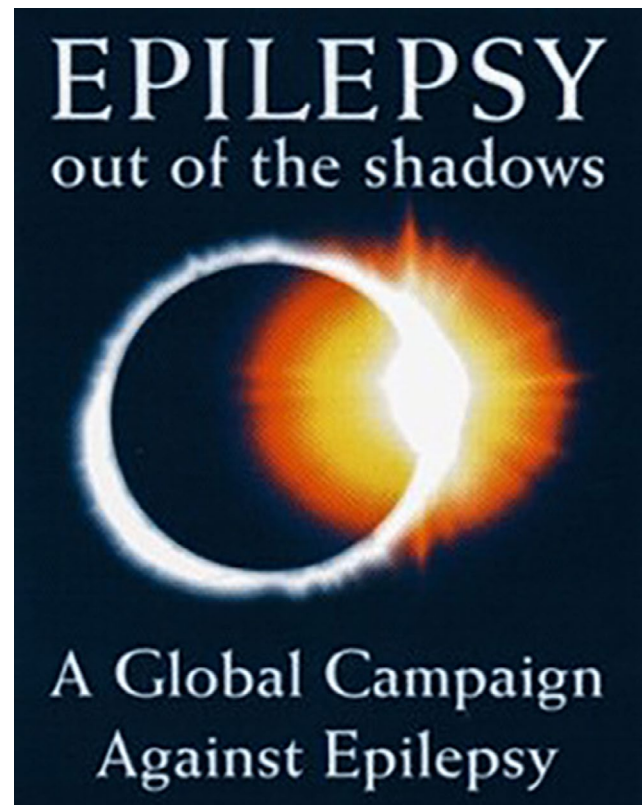
### 3.7 | Special projects

The original purpose of the League, as mentioned above, was to prosecute “Special Projects.” The collection of international statistics and then the classification scheme were early examples, and since then a number of other projects were carried out—moving the League away from just holding congresses and publishing *Epilepsia*. Some were prosecuted via the commissions and others by the executive directly and some through its regional commissions.

The Global Campaign against Epilepsy has been one of the ILAE’s most important initiatives. It is a project, formed in 1997 by the ILAE in partnership the IBE and the World Health Organization (WHO), under the campaign title “Out of the Shadows” (Figure 4). Its aim was “To improve the acceptability, treatment, services and prevention of epilepsy worldwide. The ultimate goal of the Campaign is to close the treatment gap in epilepsy.” It got off to a shaky start but achieved the notable goal of being awarded “cabinet level” status within WHO in 1999, and in 2009 the ILAE formed a Task Force which produced a strategic plan to develop the campaign further.

Eurepa, the European Academy of Epilepsy, is an example of a project run by a regional commission. It was formed in 1993 as a project of the European Region, and was followed by the establishment of similar academies in other regions. These promote the educational agenda of League by holding summer schools, online materials, fellowships, and residential and distance learning courses.

A variety of other projects were prosecuted during this period providing: a range of new educational activities including regional (migrating) courses, summer schools, and bursaries; more effective lobbying of governments and the issuing of political declarations on epilepsy; better systems of communication by the setting up an ILAE epilepsy information center, archive, website, and newsletter.



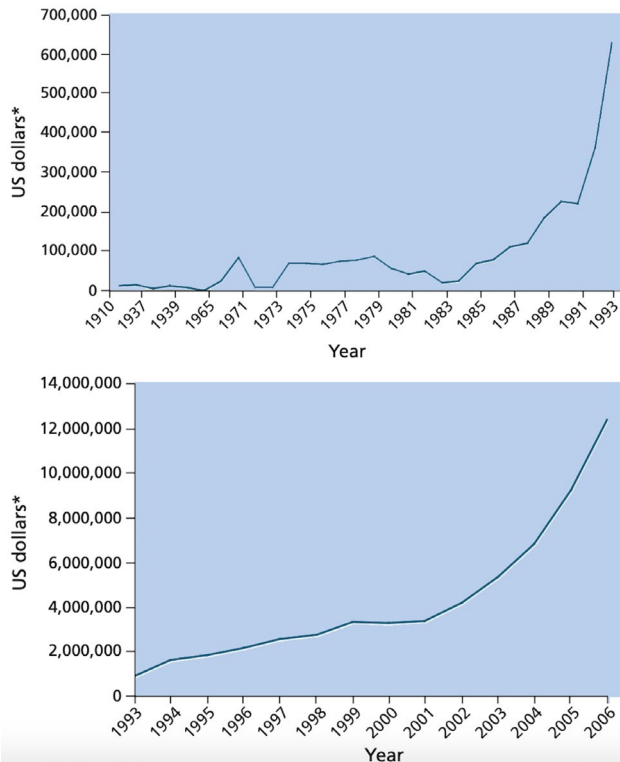
**FIGURE 4** The logo of the Global Campaign Against Epilepsy—Out of the Shadows. The Figure has been reproduced with permission from reference<sup>1</sup>

### 3.8 | Governance and finances

From its foundation, the ILAE had a constitution and was led by “an international committee” which later became known as the “executive.” The executive is elected in every 4 years by a ballot of national branches (later called chapters). Each national branch/chapter was run largely independently of the executive although bound by certain rules. As mentioned above, the regional tier was introduced in the last decade of this period. Over the 100 years, changes were made to the constitution, some wise but others heavily influenced by short-term political considerations. The executive grew in size, and as ILAE activities grew, a management committee was also constructed. For most of its early history, the ILAE had no paid staff, and the administration was conducted in an essentially amateur fashion entirely through its voluntary officers. As it grew, this became unsustainable. In 1993, secretarial support was first paid for in the offices of its President and Secretary-General, then in 1997 a professional administration was established in Hartford Connecticut, and in 2001 a second office was opened in Brussels. From 1999, the ILAE also set up and funded its own conference organizing company to arrange the international and regional congresses.

The ILAE finances developed strongly especially after 1995. The exact bank balances between 1909 and 1914 were





**FIGURE 5** The approximate monetary holdings of the ILAE, expressed in 2009 US dollar values. The Figure has been reproduced with permission from reference<sup>1</sup>

not published but did not exceed a few hundred dollars. In 1939, the ILAE's bank balance amounted to only £91 with an income of £105. In 1965, the balance was around \$2000 and income in 1961-5 had risen to around \$4000. Its monetary holdings rose to around \$35 000 by 1985 with an income of \$22 000. By 1995, the balance was around \$1 million and the annual income \$600 000. Its monetary holdings by 2006 were around \$9 million with an annual income of around \$3 million (Figure 5). This massive rise in income in the later years was fueled largely by the pharmaceutical industry, directly or indirectly through sponsorship of the League conferences (via registration fees, the exhibition and satellite sessions, and the costs of individual delegates' registration and travel), other conference income, and by income from *Epilepsia* (which by 2009 was bringing in over \$1 million dollars a year). Membership dues which were the major source of income initially, in the later years brought in only a small percentage of the total. The finances of the national chapters had always been entirely independent and outside the control of the International body, but these too were heavily subsidized by the pharmaceutical industry. The exact extent of pharmaceutical companies' financial support of the ILAE is impossible to ascertain, but by 2009, estimates of around 80% were made and are probably not far off the mark. In the earlier years, ILAE expenditure matched income closely, but in the 1990s income exceeded expenditure and surpluses

began to be accumulated. The expenditure was mainly on its commissions, congresses, special projects and administration, and the allocation of funds was sometimes controversial especially in relation to the regional commissions (to which funds were progressively curtailed) and the special projects. Once the professional administration was in place, its costs increased rapidly from around \$150 000 in 1994 to over \$1.7 million in 18 months in 1998 and this too was a matter of concern, as was the policy decided in the 1990s to accumulate a surplus to endow the administration of the League.

#### 4 | THE ACHIEVEMENTS AND CHALLENGES OF THE ILAE 1909-2009

The ILAE, over its first 100 years, grew from a tiny club to a large federation of 98 national chapters, with many activities and a large financial base. Its original work was confined largely to holding annual congresses and publishing a journal, and these two core activities have grown in importance and scope. Both are now the undisputed leaders in the field of clinical epilepsy. Its special projects, initially the gathering of statistics, also have expanded into many political and educational areas, and it has established itself as the primary provider of professional epilepsy education and via its link with the IBE and WHO, in the *Global Campaign Against Epilepsy*, a leader in epilepsy lobbying and advocacy. It has assumed the de facto leadership of many professional aspects of the international epilepsy agenda, and provides unparalleled opportunities for its individual members to network internationally and collaborate in its many activities. Similar organizations have arisen in other medical disease areas, but the ILAE has been, on many parameters of measurement, one of the most successful and admired.

Its success though has thrown up a range of challenges, some minor and transient and some more persistent. A selection of those that have particularly occupied the League's executive, at times during its first century, are touched on briefly here. First has been the need to protect its outstanding voluntary ethos, which had throughout the hundred years underpinned its success. Over the decades, many members and officers worked tirelessly, and put in large amounts of time de bono, on behalf of the League. This voluntary ethic needed to be jealously guarded, but by 2009 was viewed by many as eroded by extravagant travel arrangements and meetings, and payments in lieu to employers for time or office support. In a similar way, although the creation of a professional and centralized administration has undeniably made the ILAE more professional, more process-driven and more efficient, its costs rose exponentially in the 1990s and 2000s, and it was also viewed by some as threatening this voluntarism; these are

difficult (perhaps impossible) balances to get right and especially as cultural perspectives differed markedly between member countries. The allocation of resources is always difficult, and this has consumed much work by the executive. One source of contention has been the policy of squirreling away millions of dollars into investments and using the investment income to endow the costs of administration. This resulted in expenditure on its core mission which was far below its income, and was open to criticism in a world where there was (and remains) a desperate need for support of many epilepsy initiatives. The scale of the accumulated surpluses is thought by many to be inappropriate and the money might have been better used. There was, especially in later years, also a feeling that the problems of epilepsy in the low and middle income countries (LMIC) had been particularly neglected. This criticism had been to a great extent repudiated by the launch, and success, of the Global Campaign, but more still needed to be done. A constant challenge has been the nature of the relationship of the central body of the ILAE with its “limbs,” the national chapters and regions. Financial arrangements were not always equitable and some chapters conducted their affairs with little sense of engagement with, or duty to, the international body. A further fault line in ILAE politics, which resulted in resignations and bitter recriminations over the years, was the difficulty in balancing the scientific and social agendas of epilepsy. The most far-reaching failure was the demise of Epilepsy International. Co-operation between the League and the Bureau provides considerable added value, as demonstrated by the Global Campaign, and the inability of the ILAE and IBE to form a closer relationship has been a squandered opportunity. The viewpoint of patients has not been represented on the Leagues structures, and this too could have been given more attention. The League, at all levels, has on occasions been riven by parochial politics, nationalism, personal ambition, and personality clashes; and these seriously marred its optimal functioning. Although probably inevitable in a voluntary organization of this size, the infighting which resulted has had an opportunity cost. Much has depended on the quality of the leadership, and although in most of this period the League had been led brilliantly, this was not always the case. The nature of the ILAE relationship to the pharmaceutical industry has been another challenging issue. The ethics of accepting large sums of sponsorship money, with little control, became the subject of external criticism relating not only to the organization itself but also to individuals in leadership positions. Accountability was poor, and although major steps were latterly taken, more transparency was needed. Another recurring theme, with which the ILAE has had to grapple, has been the extent of autonomy of national chapters. Indeed, a question which bubbled to

the surface on several occasions has been whether individual members of national chapters should be signed up and pay dues directly to the international organization and not the national chapters; in other words, changing the League back to an organization of individual members as it was prior to 1935, and away from the de facto federation of national chapters which is the current model. Finally, a further issue discussed at length in earlier times was the wisdom of separating the League’s congresses, activities, and policies from those of its parent subject areas neurology, neurophysiology, and psychiatry. This subspecialization of epilepsy into an independent subject area—epileptology—and the isolation caused has downsides as well as advantages. It is arguable whether this had been always in the long-term interests of epilepsy.

As will be clear, by 2009, the ILAE was a very different organization from that envisaged by the small number of founder members who met in the Hotel Bristol in August 1909. This is a narrative of outstanding successes, and, despite the many difficult challenges it has faced and continues to face, the achievements of the ILAE have been extraordinary. In a turbulent world, the verdict of history is very much in its favor, and all those in the field of epilepsy have much to celebrate as they celebrate its 110th anniversary.

## ACKNOWLEDGMENTS

This paper draws heavily upon the book *International League Against Epilepsy 1909-2009: a centenary history*<sup>1</sup> and on the superb archive of the ILAE now held in the Wellcome Trust in London (see: <http://archives.wellcomelibrary.org>).

## CONFLICT OF INTEREST

I was a member of the ILAE executive between 1993 and 2013. I confirm that I have read the Journal’s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

## ORCID

Simon D. Shorvon  <https://orcid.org/0000-0003-0313-2001>

## REFERENCES

1. Shorvon S, Weiss G, Avanzini G, Engel J, Meinardi H, Moshe S, Reynolds E, Wolf P. *International League Against Epilepsy 1909–2009: a centenary history*. Oxford, UK: Wiley-Blackwell; 2009.